



albinism
Fellowship

Albinism Life

Issue 9 – Autumn 2005

London BBQ and Dublin Family Day



Also in this issue:

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Editorial

There is much to be positive about at the moment. The London BBQ was a great success and Treasa from Ireland reports on the Dublin Day being very successful as well. In May the training for the first group of Contact People took place in London. I joined this group of lovely people for a short time over the weekend. They really are a great bunch! And then there is the Conference in Edinburgh in November.

My apologies must go to Chris and Jayne Cain. After their giantuan efforts with their Golf Day, I failed to put it in the last magazine! An aberration on my part. We have news of last year's event which raised a staggering £15,350. We welcome any and all fundraising by the membership, large or small, it all adds up, and we will do anything we can to help you. So if you are thinking of doing something and want some advice, please do contact us.

For those of you with children of school age we have a discussion of the issues surrounding visits out of school time for the visually impaired. Outside of their familiar environment some children may need much closer supervision and the teachers may be very apprehensive for the safety of their charges. We also have some information and ideas on where to locate large print books, whether is it reading for pleasure, an examination guide or a textbook for school. If you are aiming high academically there is great inspiration from one of our members. If you have a baby or

young child with albinism then you should read Olivia's story by her mum and dad, Joan and Rob Walker.

David Burke who has a young daughter with albinism contacted the fellowship a few months ago asking for advice and information. After a discussion on the phone I realised he knew as much as me about the issue of whether to go for permanent or photochromic tints for his daughter's glasses. He had also investigated tints for cars. David kindly agreed to write up what he has researched. It is great to learn from each other and we are greatly encouraged by others offering to write a piece for the magazine. Whilst we do, of course, have to edit some articles to make them fit, we do try very hard to keep the author's style wherever possible.

Have you considered contact lenses instead of glasses? This is something that has cropped up in the past and we have some discussion for you to perhaps think about.

For those of you who use the forum for discussion, please do be aware that in the General Discussion Forum there could be undesirable people with very different values, opinions and motives to that of people in the Fellowship. We do monitor the forum but can't be on line all the time. A degree of caution is required, particularly in the General Discussion Forum because anyone on the web can go there. We have asked people and organisations not to use the forum to recruit people with albinism

for films, photo shoots, TV documentaries or similar such projects. We cannot vouch for such people and would discourage our members from doing so via this forum. If you seek fame and stardom we suggest that you get a proper agent and do things through the appropriate channels. We have asked such people and organisations to approach us first if they wish to contact our membership. In our judgement many approaches are not for the benefit or promotion of people

with albinism, but merely a means making a fast buck by exaggerating difference.

Now back on a more positive note, you should have all the details you need for the Real Lives conference. If it hasn't got to you yet it will be arriving soon, so we will hopefully see you there! Finalising costs is dependent upon some grants for which we have applied. There is a lot to look forward to!

Eds

London BBQ and Dublin Family Day – Reports

The London BBQ in June was a great success. As well as some new faces there were lots of old friends and all the trustees, some who had travelled a long way. And, of course, there was Rick Guidotti, our wonderful nomadic photographer who travels the globe promoting albinism. If you were there, you may have already spotted yourself on the front page and if not, have a look below or on the back page. Just talking to others is the main purpose of the BBQ, but we also held the AGM. Unusually we were able to do this outside, because it was warm, but not sunny or raining: ideal conditions!

A big thank you to all the Orros family, for organising the event so well again. It was a great day.

Meanwhile, in Ireland, the Family Albinism Day took place in Dublin. Treasa O' Callaghan writes:



“Caroline Casey, founder and organiser of “The Aisling Foundation” was our inspirational guest speaker. We had over fifty people present. Last year we had a medical view on albinism and this year it took on a more social view of the condition.



Caroline spoke openly about her school experiences and the difficulties she encountered along the way. She stressed the importance of self acceptance. It was wonderful for parents of children with albinism to hear about her amazing achievements.

Parents, adults, children and teenagers had the opportunity to mingle and chat. That is a very valuable part of the day.

Teenager Jessica thought Caroline was “superb” and said it was well worth the journey from Cork. My teenage daughter, Deirdre thought Caroline was “brilliant”. Sandra, a person with albinism and also a parent of two young children with the condition identified with Caroline. Sandra’s sister Martina also got a lot from the day from an adult’s perspective.

For me personally, as contact person in Ireland for the Fellowship, events made me further realize the need to create an awareness of albinism among people in general and

especially among children and teenagers. Teenagers with albinism need to build their self esteem. Also children and teenagers who are in same class as teenagers with albinism need to be more aware of the condition.”

Caroline’s great isn’t she. Others told us about that meeting too. The following, from Joanne Taylor, gives a flavour of the day...

“The first people we met were a couple from Cork and their one-year-



old little girl who also had Albinism. She was such a gorgeous little thing and I learned they were not the only people who had travelled a great distance that morning. There were people from as far North of the country as Derry to as far South as Cork and Kerry not to mention those who travelled from Scotland and England. It was great to see and meet so many people who were in a similar situation as myself. People of all ages, from

toddlers to people in their 40's or 50's. I found it extremely helpful and inspiring to sit and listen to Caroline Casey tell us about her life and experiences. So much of what she said I found I could relate to. It is great to know that you are not on your own.

A young girl asked the group for advice on how to deal with certain questions and situations at school. It got me thinking of my own sister who is due to start Secondary School in the autumn. I thought of how beneficial it would be for her to listen to all of these people share experiences and success stories and offer support to one another.

I thought of how she could make some new friends among the group. I vowed that I would phone my mother as soon as I left that afternoon and tell her all about it and tell her that she should go with Charlene next time around. And that is exactly what I did!

When I was at school I had to endure the typical taunts brought on by

youth and the lack of understanding. But, I also had some great friends who totally outweighed the taunters. Friends who I will always be thankful to for offering a helping hand by simple gestures such as passing me their copy when they knew I couldn't make out the writing on the blackboard and reading the class timetable when they knew I couldn't see the small print. These simple gestures are what made life that bit easier for me at school and they meant far more to me than 'simple gestures', they were significant gestures!

I always thought of how great it would be for everyone to be as helpful as they were to me. The only way for this to happen is for there to be more awareness, which in turn creates more understanding.



School Trips

I wonder if I may offer a few personal comments on the issues surrounding children with albinism, going on residential school trips.

I do not mean the day trips that schools regularly take children on. There should be no problems here because they are in school time and therefore, I believe, an entitlement of every child in the school. I am thinking about the longer residential trips, often to foreign shores, that many schools now organise. I cannot say one way or the other that every child has a right to go because I believe there are a number of issues to consider- I've organised some myself and I know what they are!

As a parent, of course I want my daughter with albinism to be able to do anything she sets her heart on, but I also try to see the issue from the teachers' point of view.

- Is it a trip where my daughter will require extra care and if so who should fund that cost?
- Are the staff themselves happy for her to go or are they worried about taking on – what in their eyes is - such a great responsibility?
- Does it seem that in some way my daughter's presence might create extra problems for the staff and children going?
- Is the trip organised by a private company who have stipulations for the school about who can and cannot go?

- Is there an adequate insurance policy for her special needs?

One of the trips she wanted to go on was trekking in Poland. It was vastly expensive and so we told her why we weren't prepared for her to go (which was mainly to do with cost).

Another was a French exchange where she would be paired with a French child to stay in each other's home. We wrote a letter to the school saying we hoped she would be able to go, but also stressing that if the school felt it was not possible, we would understand their decision. (It also helped that her annual review was quite soon after and we discussed the same issues with the Head.) We have since heard that they will take her and as you can imagine, she is delighted.

She also hopes to go on a tour of the Normandy beaches and we wrote the same letters and still await a reply.

I know a parent of a child in the Fellowship had a very difficult task to get her child on a skiing trip, but eventually succeeded. We spent a bit of time conversing, with suggestions of advice to the parent on how to approach the situation.

Other parents perhaps have not had any difficulties at all on school trips and that is great! But if you are experiencing any such problems, the following may be of use:

Try to see the situation from both sides, schools are faced with so much litigation nowadays that residential

trips are a nightmare and related decisions are not taken lightly. Sometimes it is just 'fear of the unknown'.

Consider that the school may be faced with incurring a massive extra cost for taking children with special needs and where do they get the money for it? Can parents help? Do you know charitable groups that might help?

Have you opened any kind of dialogue with the school about the trip? Do they know that your child might need special consideration on the trip? It's never too soon to write and express your views- you'd be amazed how much better the response to a measured rather than an angry letter is. (Sorry, that's probably me teaching parents to suck eggs, but I do know it works for me.....)

Bear in mind it could be a private

company and not the school making the refusal. Be sure of your facts and see what you can do.

Finally if the trip does go ahead and it is a success, then be sure and let everyone know! It is really nice to get the odd word or letter of thanks, saying how pleased parents were with events and of course it helps to spread the word.

But I have also experienced situations where my daughter has not been able to do things like the rest of the school and we, as a family have had to accept it. You may not agree with me, but what is the point letting her believe she will always be able to do everything others do? Isn't part of being a parent helping them to cope with the ups and downs of life, without them thinking it's the end of the world? That's how I see it and that is what I want my daughter to grow up doing.... And so far it has succeeded.

A long shot, but someone might be able to help

Elaine Ki has written to us asking for help. She is attempting trace her younger twin sister. They were born on the evening of 2nd December 1956 in Kong Wai Hospital, Hong Kong. My understanding is that Elaine and her sister both have albinism and that Elaine's younger sister was adopted to a family with the name Cheng. Given the incidence of albinism, with her known age and gender, this paragraph is worth a try. If you think you can help please contact the Fellowship and we will follow it up.

Daniel is First Class

Modesty prevents Daniel Hill, Hilary's son from telling you that he has just been awarded a 1st Class Honours Degree from Oxford University in Computing Science. He has found employment as a graduate trainee with the Bank of England, but will continue to be our Web Master for the Fellowship Website and Forum.

Public thanks to Daniel while we are on the subject of him! It just goes to show that if you do have the ability, desire and determination to gain high academic success, a visual impairment won't stop you. I'd just like to add my congratulations and trust others will gain comfort and inspiration from his personal achievement.

Large Print Copy

Encouraging youngsters to read is not always easy and reading with a visual impairment gives extra challenges. Getting hold of large print versions of texts is getting easier, but sometimes obscure and unusual titles aren't always easily found. As well as large print there are alternatives such as spoken word on tape and CD and now a new machine, the daisywheel, which is an improvement upon the conventional CD. This special machine has what looks like CDs, but they are formatted differently. The daisywheel allows the listener to adjust the speed at which they wish to listen to the narrative and bookmark places on the disk for future reference. A handy tool if you are studying a text and want to refer to a paragraph at a later point. It is a relatively new device and it is worth asking your teacher for Visually Impairment if they know about or indeed have them yet. If you wish to know more please contact us by email, telephone or by letter and we may be able to point you in the right direction.

I recently searched successfully for a large print version of 'I am David' by Ann Holm. Luckily my daughter has a switched on English teacher who gave us plenty of notice and that this would be one of the texts.

I have a list of sources that I use for large print books that I am more than willing to share with anyone that asks for them in various forms. We couldn't quite squeeze it in to this edition! I have also put this on a thread on the Forum for you to add to and comment on so everyone can have an updated and expanding list of sources of books. And if any one would like the large print copy of 'I am David' just let me know via the Fellowship.

The National Children's Blind Society will customise very many books to your specification, that is, the font style and size that you require. The books cost the same as their normal cover price but you will have to register with them first.

Mmm ..now I am thinking a large print book swap session might now be a bad idea sometime!

Contact lenses

You may think that contact lenses might be too tricky for people with albinism. You may be surprised. Some of our members do wear contact lenses successfully for a variety of reasons. For comfort, a feel good factor or just a change. Lenses come in all sorts of shapes, sizes and colours, for occasional or full time usage. Tinted lenses of course have utility as well as a cosmetic purpose. And even if you have astigmatism some types of lenses can be weighted to compensate for the irregular shape of the eye. As you blink the lens is placed in the correct position on the surface of the eye. They can obviously take some getting used to and some people never get on with them, but it is something worth considering next time you visit your Low Vision Aid Clinic or opticians. Some children do wear lenses from a young age but most people start to ask the questions about wearing them when they hit their teenage years.

I asked a few people for their thoughts on their contacts and the following from Mark gave some useful insights:

"I wore Lunelle Solaire contact lenses for several years before having to take a break from using them about a year ago after contracting a nasty case of Conjunctivitis. I am sure this was picked up from a child in the family rather than any lapse in lens hygiene. I will start using them again soon now that my eyes have finally returned to normal and are producing sufficient tears to avoid them becoming dry.

Lunelle Solaire lenses provide an all around dark brown tint that can be

fixed at 2-3 percentage points. I understand my lenses are a 40% tint.

Although they can be too dark in some environments at night (of course you do have the option not to wear them all of the time) in most daylight situations they are simply the best form of glare control that I have ever experienced and I love them.

My eyes feel open and free, I feel I can look at things without squinting too much, and the lenses soon settle to a very comfortable state. The all around protection means you don't have stray light sneaking in at the side of your eyes, as you do with spectacles. I wear a small spectacle prescription with them, that cannot be included in my contact lenses, but I think this is more about how used I am to wearing glasses than the actual optical benefit of the additional prescription.

I know not everyone needs a high prescription or benefits from one, but I do. So, I'd much rather have contact lenses even if I wear spectacles as well. It means I can have a slim stylish pair of glasses rather than large heavy lenses if I did not wear contact lenses.

Wearing contact lenses and sticking to the hygiene routine that accompanies them is not for everyone, nor is having dark tinted lenses. But for me I am happy to put up with the few disadvantages because of the numerous advantages."

That which works for Mark might not work for you, but everything is worth some consideration. As always we would like to hear what you think on this and anything else.

Press Release

Hermansky-Pudlak Syndrome Network USA Recruits for New Research Protocol

Those affected by Hermansky-Pudlak Syndrome (HPS), a rare type of albinism, now have the opportunity to participate in a ground breaking clinical trial for a drug designed to treat the pulmonary fibrosis of HPS.

The clinical trial is being run by doctors at the National Institutes of Health, the foremost research institution for HPS. Patients will be treated by some of the nation's leading experts at the NIH Clinical Center in Bethesda, Maryland. All trial-related medical care and transportation will be free to

participating patients. Cases from outside the USA will be considered on a case-by-case basis.

Those eligible must have a forced vital capacity on pulmonary function tests of below 85 percent and above 50 percent, or a diffusion capacity score below 80 percent.

If you have a breathing problem related to Hermansky-Pudlak Syndrome, or if you have albinism, asthma, and suspect you might have this syndrome you can contact:

Donna Appell tel USA
1.800.789.9477 or 516.922.4022

Contact us for more information about this – email or phone.

Fundraising for all

At the BBQ in London the subject of fundraising was raised and discussed. Why not try and use your talents or interests in some way to raise funds? For example, my wife makes and sells cards for the Fellowship. It is a little crafting hobby that she enjoys, it gives pleasure to her and the people sending and receiving the cards and raises a little for the Fellowship each year.

In November she will be bringing Christmas and birthday cards to sell at the conference. Perhaps you too have a little talent for something. It doesn't have to be on a large scale. Anything from coffee mornings, sponsored events, or making jewellery. Some people mentioned some great ideas at the BBQ so if were one of those people please have a go at something or send us you ideas and successes.

Don't forget that Schools regularly do charity fundraising and are happy to support charities close to home such as us. We have benefited from donations from non-uniform days, sponsored events and raffles.

Keynote speakers

Here we feature two of our keynote speakers at the conference.



Professor Murray H. Brilliant is Lindholm Professor of Mammalian Genetics at the University of Arizona, USA.

He is one of the world's leading researchers on albinism and we are delighted that he has agreed to join us at Real Lives in Edinburgh.

Murray's research centres on the identification of genes disrupted in several mammalian mutations that affect melanocytes (the cells usually responsible for producing melanin in our bodies). The identification of these genes can yield vital information on the normal function of melanocytes.

You can learn more about Murray's work at www.azcc.arizona.edu/whos_who/w_brilliant.htm

MILES HILTON BARBER

blind adventurer, motivational speaker

Miles Hilton-Barber has been blind for about twenty years but has not let that stop him from challenging barriers.



He is an exceptional storyteller and corporate motivational speaker. He uses his experiences as an adventurer to motivate and to inspire others to achieve their potential.

Some of you may remember first meeting Miles for years ago at our conference in Harrogate.

He is joining us in Edinburgh, back by popular demand, to update us on his adventures, further inspire some of us and reach the hearts of others with his motivational messages for the first time. See www.mileshiltonbarber.com

What's the update?

Plans for the REAL LIVES conference are well underway. The programme is agreed, we have begun recruiting exhibitors, and we are agreeing the final details with the venue and other service providers.

What else is on the programme?

You'll see the great news about two of our keynote speakers opposite. We will also hear from Mike McGowan, President of NOAH the albinism organisation in the USA on the portrayal of albinism in the cinema.

Others sessions include ones on: dealing with looking different, driving with bioptics, early years, education & work, and albinism in Africa. Social aspects include a Scottish family evening with a traditional band.

What's it cost?

We have had to delay announcing the delegate rates for the conference, but only because we are still waiting to see if we received any donations from grant making trusts that we had applied to. It continues to be a real slog to raise enough money to put the conference on. If you know anyone who can help or have any fundraising money still to send to us please let us know.

The **non-member adult rate** is £170 (£140 – Early Bird) for **non-members**. There are discounts for members and lower rates for children according to their age.

Where can I find our more?

We have already posted loads of information about the conference on our website at www.albinism.org.uk (click on Conferences) and will be keeping this up to date. We have now put Registration details on the site and have also posted them out to paid-up members on our database. You can also download fliers about the event from our website to help us promote it to people in your area.

Bino Golf 2004

In September 2004 Jayne and Chris Cain organised another of their Golf days. They raised the incredible sum of £15,350! (Fifteen thousand, three hundred and fifty pounds, it's not a typing error!) exceeding even the previous years total.

Jayne and Chris write: The event this year was held on Friday 10th September, at the Hertfordshire Golf & Country Club and consisted as usual of an 18 hole Stableford competition followed by a dinner and fundraising event.

We were very lucky to receive even more donations than usual for the auction – one lot of which was a 36 hole four-ball day at the exclusive Loch Lomond Golf Club including return flights, which raised £2000 alone! And it was due to these additional donated items that our expenses were down which, coupled with the increased amount we made on the auction, resulted in our ability to raise so much more money. In addition, we were able to improve upon the usual small amount we make on the actual charges for the golf/dinner because of a concession allowed by the club, following their mistake of a double-booking for the first date we had reserved in June. So, all in all an excellent result!

Our running total is now nearly £45,000 which is something we would never have predicted when we started this golf day, 6 years ago.



None of this of course, would have been possible without our guests and sponsors mentioned below:

Main Sponsors:

Tesco (Guy Digby)

**Dale Dobban - The Big Picture
(Hatfield, Herts)**

Rod Taylor

Nicola Bull

Paul & Sarah Millard

John & Linda Kearey

Nick Macknight & Jacky Steele

Barry & Cynthia Steele

Grant Gleghorn & Anita Carr

Mike Styles

Dean & Jackie Brough

Jude Fuller & Lyn Healy

Rebecca Ross

And of course there were many others who bid and bought so generously.

We would just like to add our thanks to Jayne and Chris and everybody who has given so generously...Eds

Linda McKerchar writes from Perth in Scotland



Ryan, the little chap in the picture above, is starting school after the summer holidays. The school is Craigie Primary School in Perth, Scotland. The Parents Association (of which, I am to be vice-chair next term) have been busy with a sponsored fun-run and have decided to donate to charities which help the children who attend the school. As Ryan has albinism, they have donated £200 to the Fellowship. We are looking forward to the Conference in Edinburgh next year.... as this is sooo much closer to home.



These two "ladies" ran the Ireland mini-marathon, raising almost 3,000 Euros. An amazing achievement! You know who you are and we thank you!

The Local Contact Persons Initial Training

My experience

by Sarah Fellows

At 4 p.m. on a sunny Saturday in May, fifteen people arrived at a hotel in London to facilitate and take part in the 'Initial Training of Local Contact Persons for the Albinism Fellowship'. As a participant, I was not sure what to expect. We had all applied for these positions and had attended an interview, so it felt to me, rather like the first day at a new job. However, one in which there was a much more personal element than any other, as I knew we would all have a varied experience of albinism and were motivated to provide assistance and information to others locally.

The overall purpose of the Local Contact Person is to provide local information, advice and support for people with an appropriate interest in albinism. To represent the Albinism fellowship locally and encourage interest in and support for its work. Practically, this includes talking to people who have experience, or are new to some of the challenges of albinism, by phone, mail or in person if required. Arranging an opportunity for people to gain more knowledge, socialise locally and having an input



Rick Guidotti captured!

to or responding to local media as appropriate.

We had an enjoyable and stimulating two days. The Local Contact Persons came from all over the U.K. we have a wide variety of skills and experience between us, both of albinism and professionally. Amongst the group there are people with albinism, and parents of children, who range from those successfully in higher education, to those just starting in school.

During the formal sessions we were given an overview of the Fellowship and how, as a Local Contact Person to represent the organisation. We were provided with guidance about how to manage the scope and limitations of the role, where to seek extra support and ensure our knowledge of albinism

was accurate. Some of us had concerns that we were not 'experts', but this is an important factor of the role. Albinism is a complex condition, affecting people in many different ways, physically, practically and emotionally, the Local Contact Persons are not qualified to offer specialist individual advice, but can guide people to appropriate organisations and act as a listening ear and support throughout this process.

As those of us who have attended the conferences will be aware, some of the most useful discussions take place away from the formal sessions, we all made good use of this time.

The course was professionally facilitated by Robin Spinks and Mark Sanderson, who developed the course materials. Lorna Stacey and Gill Walker's organisational skills enabled all to run smoothly and the effervescent Rick Guidotti shared his continuing work with the Positive Exposure project, which has done much to portray the beauty of albinism on an international scale.

So, armed with new knowledge, confidence and friendships we are set to go – please contact us.

(In the next edition we will have more on this for you...Eds)

Photochromic vs Tints

Following an enquiry and then a conversation, one of members, David Burke, kindly agreed to write up what he researched about tinted car windows and the issue of whether tinted or photochromic lenses are best for a younger child.

Car Window Tints

Applying tints to car windows has become increasingly popular over recent years. However, it may be more than a fashionable addition for individuals with albinism travelling in a car by reducing the glare and affect of photophobia. As you'll be aware, the most common type of tint is black. However, these are available in

a range from grey to almost total black. In addition, a range of colours is also available.

The colour and strength of tint may be assessed on an individual basis depending on whether photochromatic or permanent tint lenses are used and the degree of photophobia experienced.

Photochromatic Tints

A user of photochromatic lenses may benefit most from selecting a window tint from the black range due to the lenses not adjusting inside a car. The choice on offer (% of light blocked out):-

Privacy (95%) (or if you wish to feel like a celebrity!)

Black (80%)

Dark Grey (65%)

Grey (50%)

Permanent Tint Lenses

A user of permanent tint lenses may prefer to select a colour of window tint that is sympathetic with their lens tint. The colours on offer (% of light blocked out):-

Red (65%)

Blue (65%)

Green (65%)

Pink (50%)

Pale Blue (50%)

Yellow (50%)

If you choose a window tint from the colour range, it has the added advantage of giving you the perfect excuse to change your car to match the window tint!

Legal

Just a short note on the legality of car window tints. As far as the author is aware, the windscreen and front side windows of a car must let in at least 70% of light to be legal, but the other windows are at the discretion of the owner. However, it is advisable to check with your local Traffic Police and the Car Window Tint company before proceeding with any work.

Glasses – Photochromatics Vs Permanent Tints

Our baby daughter recently received a prescription for her first set of glasses due to albinism. We thought it would

be a straightforward case of taking the prescription to an Optician until the Ophthalmologist asked: “Photochromatics or Tints?”

Our objective was to choose the type of glasses that would reduce the effect of photophobia while retaining our daughter’s useful vision both indoors and outdoors.

We asked users of both types of glasses as well as several professionals. We soon realised the more people we asked, the more varied answers we received (and the more confused we got), with no consensus of opinion. In the end, we sat down and wrote out the following information on one sheet of paper:

Photochromatics – Pros

- Good at adapting to variable environmental conditions
- Relatively clear indoors, thereby maximising useful vision
- Only need one pair of glasses both indoors and outdoors

Photochromatics – Cons

- Do not darken when in car nor indoor Precinct, thereby reducing use of functional vision due to the distress caused by the affect of photophobia
- Adjustment time for lenses to react when coming indoors from outside and vice versa

(Improvements with each new version of Photochromatics)

Outdoors on a very bright day:

- Lenses may darken too much thereby reducing functional vision

OR

- Lenses may not darken enough to cope effectively with very bright conditions thereby reducing use of functional vision due to distress caused by the affect of photophobia

(Initially, a mid grey range may be most appropriate to assess reaction as tends to be a case of trial & error)

Permanent Tints – Pros

- Reduce the affect of photophobia in car and indoor Precinct conditions thereby maximising use of functional vision
- No adjustment time required coming indoors from outside and vice versa

Permanent Tint – Cons

- Not adaptable to changing environmental conditions and therefore offers a compromise solution which might not be appropriate at extremes of brightness/darkness
- Might be too tinted indoors thereby reducing functional vision. However, can increase the level of background light if at home.

- Might not be tinted enough if very bright day thereby reducing use of functional vision due to distress caused by the affect of photophobia

- May need an indoor pair of glasses as well as an outdoor pair with different level of tint

As you can see, the pros & cons of photochromatics versus permanent tints is almost a mirror image of each other. Consequently, neither photochromatics nor permanent tints may be suitable across the board for every user, but rather the pros & cons of each type of lens should be assessed on an individual basis.

(P.S. We chose photochromatics for our baby daughter)

Eds comment: I have put this issue up for discussion in the member's section of the Forum on the Website. I would be interested to hear what others think and what they have done in the past and are doing now. Photochromic lenses are developing all the time and their reaction speeds are being improved all the time. In a few years this might not be an issue. In the past my daughter has had two pairs of tinted glasses. One for outside that cut down 60% of the light and another that cut down about 40% for indoors.

Encouragement to others from Jane & Rob Walker

Olivia turned six this month. She has albinism but achieves everything her peers do. Olivia attends a small primary school, near Hull, and has just finish Year One. Since the start of the last term Olivia and six other class mates were “moved up” into the Year 2 classroom to do Year 2 work as they were all exceeding targets for Year 1 and finding things a bit too easy. A fantastic school!

Olivia has a 17.5 hrs per week CSA, who basically makes sure all desk top work is enlarged and that Olivia is correctly seated in class. She is supported amazingly by the Education Service for the Visually and Hearing Impaired. I cannot express enough how wonderful these people are, Olivia has already been issued with her own laptop and at 5 is practising 10 minutes per day touch typing, she is using a rainbow machine for guided reading which some of the fully sighted children also like to be involved with. She is has received a wonderful end of year school report showing how much she contributes to classes. When we first found out about Olivia’s albinism, we were very worried about how she would cope with school life, but we shouldn't have worried because she is excelling at everything. The school has just had their sports day, which is competitive sports with individual races. Olivia

chose to run in all six races and achieved a 2nd place in the obstacle race!! and 3rd in the bean bag race! All others races she gave 100% too, but was tiring by the end of the afternoon (it didn’t help that Olivia and her friend Aimee were racing each other up the track throughout the drinks break).

Olivia learned to ride her bike without stabilisers by 5 because of her daddy’s perseverance and rides up and down the street on her own. On Fridays her treat is to be picked up with her bike and she rides home from school, dodging her class mates with dad running somewhere behind! Olivia is also a natural swimmer, is on track for her 25m badge and also enjoys Judo.

We have holidayed in Western France where the temperatures are about 26C. Olivia was taken to Majorca when she was 4 and whilst we were there Majorca saw their highest temperatures for 20 years, in the high 30's, but with the right sun protection and the right attitude to life, anything is possible. So if anyone thinks they “can’t do something” because of Albinism, all we can say is don’t give in. Don't let Albinism be a reason for “not doing” something. Don't get us wrong, it’s not all plain sailing and we have lots of “moments”, but overall we cope and get on with it.

Where will you put yours? – We have put the big picture on the back cover so that you may cut off the back page and use it like a mini poster to put on your fridge, memo board, or where ever you choose.



The Albinism Fellowship Barbeque 2005
It's good to belong!